

May 29, 2001

*Achieving Success for All
Children and Youth
with Special Health Care Needs*

A 10-Year Action Plan to Accompany Healthy People 2010

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Goal #4: Families of children with special health care needs will partner in decision-making at all levels and will be satisfied with the services they receive.

Active partnership between families and professionals is the cornerstone of family-centered care. Family-centered care is a process to ensure that (1) the organization and delivery of health care services meet the emotional, social, and developmental needs of children; and (2) their families are integrated into all aspects of the health care plan. It encourages families to participate as integral partners in the medical home and to work with their children's health care professionals in making informed health care decisions. It recognizes, in fact, that families are the ultimate decision-makers for their children.

Family-centered care goes beyond that, however. It also supports families in learning more about how health care is financed, delivered, and organized so they can become involved in decision-making on a much broader level. More than anyone else, families understand the barriers to accessing needed quality services, close to home, that they can afford and navigate easily. By telling their stories and sharing their unique expertise, they are able to assist other decision-makers as no one else can. The inclusion of families in decision-making and policy formulation at the community, State, and Federal level is critical if we are to improve services and supports to children with special health care needs.

Families also have a unique ability to act as advocates on behalf of their children and others. Family advocacy has been successful when families form relationships with other stakeholders in the policymaking process and advocate for legislation on behalf of children with special health care needs. Families have also been essential in providing information to other families about accessing resources, navigating the system, and participating on task forces and commissions.

Clearly over the past few decades, remarkable advances have been made in bringing families to decision-making tables and increasing their satisfaction with services for children with special health care needs. Family Voices, which began as a small organization of families of children with special health care needs, now provides support and education to both families and providers in every State. Through their leadership and that of many other family organizations, families are now in the forefront of national, State, and community efforts on behalf of these children, whether it is in the area of program, policy, or practice.

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However, there great challenges remaining, including how to implement full participation in decision-making and ensure that all families, including those from culturally, linguistically, economically, and geographically diverse backgrounds, are satisfied with the services they receive.

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Action Step 1

Assure family-professional collaboration as a key element of the medical home.

Strategies:

- Encourage medical homes to adopt policies and practices that support family-centered care, family/professional partnerships, and cultural competency.
- Assist medical homes to actively partner with families in: (1) professional development activities designed to enhance providers' interactions with children, family, and community; (2) family advocacy and leadership efforts; (3) efforts to ensure that the medical home is the central point of access for the materials and resources that families and providers need; and (4) activities to enhance the meaningful participation of families in care planning and implementation.
- Institutionalize family-to-family support as an essential element of the medical home.

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Action Step 2

Enhance family-professional collaboration at all levels to improve the system of care for children with special health care needs.

Strategies:

- Develop a “public awareness” strategy highlighting the critical role of families as decision-makers. Among others, this strategy should target families, Federal, State, and community agencies, CEOs and CFOs of businesses and health care organizations, neighborhood/community groups, professional organizations, university training programs, legislators, Governors’ Task Forces, and advocacy groups.
- Encourage schools of public health, medicine, nursing, social work, occupational therapy, and physical therapy, as well as other professional schools, to incorporate specific elements and indicators of family-centered care, family/professional partnering, and cultural competency as standard components of educational curricula for health care professionals.
- Support the use of families to assist in the design and delivery of medical and other health professional education.
- Assure, through guidance, strategic planning, and contract language and requirements, that MCHB and its State counterparts are: (1) modeling family-professional partnerships in all activities, including SPRANS projects; and (2) demonstrating cultural competence by implementing the principles and concepts recommended by the National Center for Cultural Competence.
- Include families in all workgroups, advisory committees, etc. at the local, State, and Federal levels and provide adequate compensation to them for this work.
- Provide Federal funding to establish a Family-to-Family Health Information Center in each state.

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Action Step 3

Support the participation of traditionally under-represented families.

Strategies:

- Institutionalize special programs and supports for fathers as caregivers and partners with mothers.
- Catalog, assess, and develop an easily accessible databank for health and related materials in multiple languages.
- Support the services provided by medical interpreters, design standardized training for these interpreters, and develop quality indicators for interpreter services.
- Provide cross-cultural pre- and in-service training to providers and other staff.
- Enhance outreach and support to culturally diverse providers and community organizations.
- Expand outreach to families who traditionally do not access health care services for their children with special health care needs on a regular basis. Outreach should be designed to identify the barriers that keep families from establishing and maintaining successful relationships with health care providers, schools, and community agencies and to develop concrete strategies to address these barriers.
- Develop performance measures for the Title V Block Grant application related to cultural and linguistic competence, similar to the “family participation” measure, in order to provide opportunities for States to report their efforts in this area and to monitor progress. Incorporate similar measures into the new reporting system for Special Programs of Regional and National Significance (SPRANS).
- Increase the training professionals receive in working with children and families from culturally diverse backgrounds in all professional development programs.

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Action Step 4

Develop and promote adequate measures for determining family satisfaction with health care services.

Strategies:

- Create hotlines or other means through which families can register quality and access concerns. These can also serve as a clearinghouse for information about the cumulative experiences of families.
- Develop appropriate measures to examine family satisfaction with critical elements of the system of care, such as care coordination, health care financing, access to primary care, specialty care, subspecialty care, and therapies, decision-making, provider-family communication, and transition.
- Develop strategies for assessing both access to and quality of care that incorporate these measures of family satisfaction, as well as a continuous loop of ongoing feedback to and from families.